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Alzheimer's Disease Demonstration Grants to States Program: Cross-State Report on Initiatives Targeting Limited- English-Speaking Populations and African American Communities

Final Report

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ALZHEIMER'S DISEASE DEMONSTRATION GRANTS TO STATES:
CROSS-STATE REPORT ON INITIATIVES TARGETING LIMITED
ENGLISH SPEAKING POPULATIONS
AND AFRICAN AMERICAN COMMUNITIES

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EXECUTIVE SUMMARY

One of the main goals of the Alzheimer's Disease Demonstration Grants to States (ADDGS) program is to expand and improve services for underserved populations, including racial and ethnic minorities. Alzheimer's disease among minority populations is of policy concern for several reasons. Some minority populations:

- may be at higher risk of Alzheimer's disease,
- often are less knowledgeable about Alzheimer's disease and its progression, and
- often do not start to use services until late in the disease and tend to underutilize services at all stages of the disease.

This case study examines four ADDGS grants that focus on minority populations to analyze what type of activities they conduct, what barriers they confront serving minority populations, and what strategies they use to overcome these barriers. The Illinois grant concentrates on limited-English-speaking older persons speaking Arabic, Assyrian, Bosnian, Hindi, and Urdu; the Florida, Kentucky, and District of Columbia grants focus on African Americans.

ES.1 Overview of the Selected Grants

The four states examined in this case study engage in a wide range of activities to promote knowledge about Alzheimer's disease and access to services.

Limited-English-Speaking Elders: Illinois

The Illinois grant: (1) works with the Coalition of Limited English Speaking Elderly (CLESE), an organization representing 45 Chicago-area ethnic organizations providing services to older people who live in the targeted ethnic communities; (2) provides outreach and education, as well as formal and informal caregiver training, to ethnic organizations, physicians, and the community; and (3) funds ethnic organizations to provide dementia-relevant services.

African Americans: District of Columbia, Florida, and Kentucky

The District of Columbia grant: (1) works with the African American faith-based community to conduct education and outreach; (2) works with African American faith-based organizations to build community coalitions; (3) offers a cash and counseling-like program for African Americans; and (4) implemented Montessori-based programming in adult day centers serving mainly African Americans.

The Florida grant: (1) provides information and outreach to the African American faith-based community; (2) works with African American faith-based congregations to recruit volunteers to conduct door-to-door outreach in their neighborhoods; and (3) manages several other initiatives—increasing long-term care services, providing services to address problems of wandering, establishing a task force on Alzheimer's disease, creating a priority-setting system for targeting clients, and expanding the crisis intervention information and referral helpline.

The Kentucky grant: (1) works with the African American faith-based community to provide information and outreach, (2) provides dementia assessment and diagnosis in the African American community, and (3) involves the faith-based community the identification of persons in need of free memory checkups and other dementia services.

ES.2 Barriers and Strategies for Overcoming Them

The grantees identified four main barriers to serving ethnic and racial minority populations and implemented strategies to overcome them. The main areas they identified as barriers are:

- trust from and access to the community,
- cultural beliefs and knowledge about dementia,
- language, and
- the role of the family.

Trust from and Access to the Community

Grantees identify establishing trust from and access to the community as the principal barriers to implementing their initiatives. Barriers include the following: (1) minority communities are often wary of people, organizations, and institutions that are not part of the community; (2) ethnic and racial minorities may believe that outside organizations “use” the communities for their own benefit and do not contribute to the communities’ long-run well-being; and (3) minority communities may distrust government agencies, perceiving them as prying into personal finances and other family issues as a condition of providing aid.

Strategies used by grantees to overcome these problems include the following: (1) projects invest substantial leadership resources into gaining knowledge about and the trust of the community; and (2) grants involve the racial or ethnic community by hiring individuals from the community, working with faith-based or service organizations with strong ties to the community, locating services physically within the community, and establishing advisory committees composed of community members.

Cultural Beliefs and Knowledge about Dementia

Some ethnic and racial minorities have cultural beliefs and understandings about dementia that are different from the mainstream culture and that may impede their use of services. Barriers include the following: (1) awareness and understanding of Alzheimer’s disease is low in some ethnic and racial communities, especially those facing competing demands such as low income, high levels of unemployment, and lack of health insurance; (2) minority populations may be more likely to identify Alzheimer’s disease as “normal aging”; and (3) in some cultures, there may be particular historical reasons (e.g., post-traumatic stress disorder among Bosnian refugees) that family members have cognitive impairment that are not related to Alzheimer’s disease. The main strategy that grantees use to address these barriers is to be

cognizant of cultural differences and to modify educational and other material to better suit the community.

Language

Language is a means for people to communicate, but it can also be a barrier to educating people about Alzheimer's disease and providing them with services. These barriers include the following: (1) in some communities, the ability to speak and read English may be limited, and (2) commonly used English-language terminology about Alzheimer's disease and cognitive tests may not translate well into other languages.

Strategies used to overcome these barriers include the following: (1) instead of using the difficult-to-translate, emotionally laden term "Alzheimer's disease," grantees use the term "memory loss"; and (2) educational and outreach material is translated from English into other languages using terminology appropriate for a modest reading level.

Role of the Family

In virtually all cultures, families play major roles in caring for people with dementia. In minority communities, families have large caregiving responsibilities because of differing cultures and norms, language barriers, reaction to past discrimination, and difficulties accessing services. Some barriers that the grantees encountered in providing services to minority populations include the following: (1) cultural norms establish expectations for families to "take care of their own" without the help of others; (2) families may perceive offers of help as an insult to their ability to provide care; and (3) families may be intensely protective of their privacy, seeing services such as volunteer respite or support groups as "getting into family business"; and, (4) respect for elderly relatives may preclude adult children and other relatives telling seniors what to do, even if they are not cognitively intact.

Some strategies that grantees use to address these barriers include the following: (1) the differences in caregiving norms are accepted by the grantees and ways are sought to present services in a culturally acceptable fashion; and (2) the family decisionmaking process is acknowledged and services work with rather than against that structure.

SECTION 1

INTRODUCTION: OVERVIEW OF THE ADDGS PROGRAM AND CASE STUDIES

Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. A person with late-stage Alzheimer's disease requires constant supervision, support, and hands-on care. While many persons with Alzheimer's disease are admitted to nursing homes, the majority of people with the disease live in the community, where their families provide most of their care.

To improve services to persons with Alzheimer's disease, Congress established the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, which is administered by the U.S. Administration on Aging. The program's mission is to "expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard-to-reach and underserved people with Alzheimer's disease or related disorders" (U.S. Administration on Aging, 2006).

The ADDGS program addresses how to deliver effective services to persons with Alzheimer's disease and other dementias and their caregivers, especially to underserved and hard-to-reach populations. The purpose of the ADDGS program is to enhance the ability of states to provide the services and supports needed to sustain the community-based Alzheimer's disease care system. The program does this in two ways: by demonstrating innovative service models of Alzheimer's services that can be replicated and sustained in the community and by stimulating systemic change to increase the responsiveness of states' overall long-term care systems to the needs and preferences of persons with dementia and their families.

This paper is one of four case studies conducted by the ADDGS National Resource Center in 2006 on the activities of selected state programs.¹ The goals of the case studies are to:

- document "promising practices,"
- identify policy issues relevant to providing services to people with Alzheimer's disease and their families,
- identify implementation barriers and ways of overcoming them, and
- assess how selected states are addressing the goals of the ADDGS program.

This case study examines four ADDGS grants that focus on minority populations to analyze what type of activities they conduct, what barriers they confront to serving minority populations, and what strategies they use to overcome the barriers. The Illinois grant concentrates on limited-English-speaking older persons speaking Arabic, Assyrian, Bosnian,

¹ The other case studies focus on Michigan, which concentrated on a mental health perspective on Alzheimer's disease; Minnesota, which uses the Chronic Care Networks for Alzheimer's Disease principles to focus its initiatives; and New York, which concentrated on integrating care for developmentally disabled people with Alzheimer's disease.

Hindi, and Urdu; the Florida, Kentucky, and District of Columbia grants focus on African Americans. Information for this report was gathered through a review of U.S. Administration on Aging documents and telephone interviews with grantee staff and partners during August and September 2006.

Readers interested in other ADDGS initiatives to improve services for ethnic and racial minorities may want to read the National Resource Center's case studies on California, which includes information on its work in Hispanic, African American, and Asian Pacific Islander communities (http://www.aoa.gov/alz/Public/alzabout/Case_Studies/CA_Case_Study.pdf) and Oklahoma (http://www.aoa.gov/alz/Public/alzabout/Case_Studies/OK_Case_Study_1_06_Final.pdf), which includes information on its work in African American communities. A separate case study profiles several ADDGS grants which targeted Hispanic/Latino communities.

SECTION 2 BACKGROUND

Alzheimer's disease in minority ethnic and racial populations is of policy concern for several reasons. While there is great diversity across minority populations, these groups:

- may be at higher risk of Alzheimer's disease (especially African Americans),
- are often less aware and knowledgeable about Alzheimer's disease, and
- often do not start to use services until late in the disease and tend to underutilize services at all stages of the disease.

First, although measurement of cognitive impairment in minority populations is complicated, there is evidence that some minorities are at higher risk of Alzheimer's disease. One study found that 17 percent of older African American men and 17 percent of older African American women experience cognitive impairment, compared to 9 percent of older white men and 8 percent of older white women (Demironovic et al., 2003). Another recent study found that the incidence of dementia among African Americans was greater than in other groups even after controlling for conditions such as high blood pressure, heart disease, stroke, and diabetes that have higher prevalence among African Americans (Shadlen et al., 2006). On the other hand, while data are incomplete in terms of the cause of death, blacks have lower reported death rates from Alzheimer's disease than whites—22.2 deaths per 100,000 population for whites compared to 16.6 deaths per 100,000 population for blacks from 1999 to 2005 (Michigan Department of Community Health, undated).

Second, some minority groups are less aware of Alzheimer's disease as a disease and tend to regard it as part of normal aging. In one study, African Americans showed less awareness of facts about Alzheimer's disease than whites, and indicated less perceived threat of the disorder (Roberts et al., 2003). In first-generation Hispanic/Latino families, Alzheimer's disease is sometimes viewed as a curse or punishment for previous bad deeds. Care providers working with this population report common use of folk remedies and nonmedical cures (Montgomery et al., 2001).

Third, minorities tend to have lower use of services, often not using them at all or starting use at higher levels of functional disability than whites. For example, despite the emotional costs of caring for persons with Alzheimer's disease, African Americans underutilize community-based long-term care services as a result of how caregiving is perceived, the high costs of care, lack of third-party coverage, absence of culturally relevant formal services, and racial discrimination (Harrel et al., 1987; Hinrichsen & Ramirez, 1992; Lampley-Dallas et al., 2001; Manley et al., 1999; U.S. Congress, Office of Technology Assessment, 1990). This lower use of community services is especially striking because African Americans are institutionalized at a lower rate than whites despite higher disability rates (Manton & Gu, 2001).

The use of services across ethnic and racial groups can be complex. In their study of the respite care provided through the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, Montgomery et al. (2001) found the following:

Different ethnic groups have distinct trajectories of service use over time. Although Black/African-American elders use day care for a longer duration period than does any other group, the amount of day care used each month diminishes over time to a point that they become the group with the lowest level of use after an extended period of use. In contrast, as a group, Hispanic/Latino elders use day care for the shortest duration period, but their level of use is the highest of any ethnic group at the time of initial use. Also, they maintain this higher level of use relative to Whites and Blacks/African-Americans throughout the duration of their use. Clearly, the pattern of day care use for Hispanics/Latinos is distinct from that of both Whites and Blacks/African-Americans, but the two groups do not differ in the total number of hours of day care use. Blacks/African-Americans tend to use smaller quantities over a more extended period of time, while Hispanic/Latino elders use high quantities for short periods.

Respite staff working with African American and Hispanic/Latino communities found a strong sense of self-sufficiency and a general distrust of government services within these populations (Montgomery et al., 2001). A pervasive belief in both communities is that caregiving should be provided by the family. According to the study, many African American families regard free government assistance for Alzheimer's disease as a welfare handout which they will not readily accept. In addition, respite staff members observed reluctance on the part of African American families to accept white care providers. In addition, according to respite staff members working in predominantly Hispanic and Latino neighborhoods, fatalistic religious beliefs and the social stigma associated with Alzheimer's disease contribute to family reluctance to seek outside help. Limited English and relatively low levels of literacy isolated Hispanic/Latino clients from mainstream sources of information and aid. Compared to White and Black/African American caregivers, Hispanic/Latino caregivers reported the highest communication barriers to utilization of respite services.

Florida and Kentucky ADDGS grantees offered quantitative evidence suggestive of underutilization of services by African Americans in those states in their initial grant proposals. African Americans comprise 6.8 percent of Florida's population age 65 and older, but constituted only 4.4 percent of clients served by Memory Disorder Clinics in FY 2002–2003 (Florida Department of Elder Affairs, 2004; U.S. Administration on Aging, 2006). Similarly, Kentucky reported underutilization by African Americans of the Memory Disorders Clinic that is part of an internationally recognized Alzheimer's Disease Research Center located at the University of Kentucky's Sanders-Brown Center on Aging (Kentucky, 2003). Of the 1,688 patients who have been diagnosed at this clinic, only 60, or 3 percent, were African American, and only 5 African American patients, approximately 2 percent, are enrolled in the Research Memory Disorders Clinic.

SECTION 3 OVERVIEW OF THE GRANTS

This section briefly summarizes four Alzheimer's Disease Demonstration Grants to States (ADDGS) grants which focus on minority populations. The Illinois grant focuses on limited English-speaking elders; and the District of Columbia, Florida, and Kentucky grants focus on African Americans. For each state, the name of the project, the targeted minority population, grant partners, project goals, and a description of project activities are provided.

3.1 Limited English-Speaking Elders: Illinois

Name of Project

Illinois Rural and Limited English Proficient Populations Alzheimer's Disease Demonstration Project (2005–2008)

Target Minority Population

Limited-English-proficient elders, particularly older people who speak Arabic, Assyrian, Bosnian, Hindi, and Urdu in the Chicago area. The project also serves rural elders.

Grant Partners

- Illinois Department of Public Health, Office of Health Promotion (Grantee)
- Illinois Department of Aging
- Regional Alzheimer's Disease Assistance Centers
- Northwestern University Medical School Cognitive Neurology and Alzheimer's Disease Center
- Coalition of Limited English Speaking Elderly (CLESE) and its member organizations: Arab American Family Services, Assyrian National Council of Illinois, Assyrian Universal Alliance Foundation, Bosnian/Herzegovinian American Community Center, Metropolitan Asian Family Services, Social Services Assisting Neighborhood Arab American Development (SANAD), and Urhai Community Service Center
- Alzheimer's Association, Greater Illinois Chapter

Project Goals

- Increasing the number of persons with memory problems who receive appropriate assessment, diagnosis, and treatment.
- Increasing the number of persons with Alzheimer's disease who receive home and community-based services.

- Providing support and training for caregivers.
- Improving coordination between partners and other community-based organizations.

Grant Activities

This project builds on a previous ADDGS program (2001–2004), which focused on Chinese, Korean, Polish, Russian, and Spanish-speaking elders. The grant works through an association of ethnic service organizations—CLESE—to reach a target population of underserved ethnic seniors.

CLESE represents 45 Chicago-area ethnic organizations serving limited-English-proficient elders in 26 ethnic groups. CLESE members provide supportive services, English language and citizenship classes, health screenings, and escort and interpreting services for elderly immigrants, refugees, and migrants. Nineteen ethnic organizations provide homemaker and/or adult day services clients as well. As a coalition, CLESE promotes understanding, sensitivity, and insight into cultural variations, helping to remove barriers that prevent access to services. By contracting with CLESE, Illinois government agencies and other organizations can reach minority communities through the ethnic agencies. This model of using CLESE as a coordinating agency is currently being used by the Illinois Departments of Aging and Public Health and Human Services and the Chicago Department on Aging. CLESE, with three full-time staff members, serves as coordinator, intermediary, and interpreter between the funders and the ethnic agencies.

Outreach and Alzheimer’s Disease Identification—Based on the experience from the earlier ADDGS grant, Alzheimer’s disease awareness and education for the ethnic agencies and general community is a necessary first step before other activities take place. The project staff work with CLESE and its member agencies to provide outreach. A resource guide on Alzheimer’s services, developed during the previous ADDGS program, was updated, translated (translations were provided by CLESE), and distributed by CLESE member agencies.

As a way of identifying people in need of services, the Illinois Department on Aging searches its database to identify home care clients who scored poorly on the Mini Mental Status Exam, which is an indicator of cognitive impairment. Participating agencies then contact identified clients and families to discuss the need for appropriate assessment, diagnosis, and treatment and request permission for referral for a clinical assessment. It may take several home visits before the family is comfortable with enrolling their elder family member in the program. Participating ethnic agency staff members are trained to screen for “memory problems” to help identify clients, who are then referred for medical assessment.

Caregiver Trainings—Community members and staff at ethnic agencies typically do not have an extensive understanding of Alzheimer’s disease as a medical problem, often viewing it as part of normal aging or believing it is caused by an injury. A basic presentation on Alzheimer’s disease, including the difference between normal aging and memory problems, has been translated into the five target languages and presented to agency staff and community residents by the Alzheimer’s Association.

Caregiver training draws on the “Savvy Caregiver” and “Making Sense of Memory Loss” programs and are provided in the ethnic community’s language. Based on the experience from the previous grant, traditional support groups are unknown or unacceptable to many ethnic groups because personal information is not shared outside the family. Generally, caregiving is shared by a number of immediate and extended family members; there is not one “caregiver.” Immigrant and refugee families expect to provide care for their older members and are offended by any implication that providing the care could be a burden. In the countries that the current participant groups come from, families provide the care that is needed (although wealthy families may also have servants to help). However, family members appreciate information that is practical and helps them provide better care for their loved ones. Presentations on managing difficult behaviors have been very well received.

Home and community-based services providers and other local agencies are being trained to screen for dementia and on the importance of assessment, diagnosis, and treatment. CLESE facilitates the training provided by the Illinois Department of Public Health, the Alzheimer’s Association Greater Illinois Chapter, and Northwestern University’s Cognitive Neurology and Alzheimer’s Disease Center. To improve linkage to medical providers, a Northwestern University staff person offers education and training on Alzheimer’s disease assessment, diagnosis, and treatment to bilingual community physicians. At the time of the interviews for the case study, ethnic agency staff had escorted 25 people for a comprehensive assessment and treatment from their community physician.

3.2 African Americans: District of Columbia

Name of Project

DC Alzheimer’s Awareness and Care Program Grant (2004–2007)

Target Minority Population

African Americans are the target population. The U.S. Census Bureau estimated that 66 percent of persons age 65 and older in the District of Columbia were African American in 2005 (U.S. Administration on Aging, 2006). Fully 89 percent of the clients of the District of Columbia Office on Aging in 2003 were African Americans (District of Columbia Office on Aging, 2004).

Grant Partners

- District of Columbia Office on Aging (Grantee)
- Alzheimer’s Association, National Capital Area Chapter
- HomeCare Partners
- Churches in selected parts of the city

Project Goals

- Mobilizing the African American faith community to create community coalitions that raise awareness of Alzheimer's disease and increase utilization of services by this group.
- Expanding the range of services available for people with Alzheimer's disease by testing a form of consumer-directed home care services.
- Introducing a new type of programming into adult day care centers.

Grant Activities

Faith-based Initiative—The DC grant works with African American faith-based organizations to conduct outreach on Alzheimer's disease and to run programs. During the first month, a steering committee consisting of the project partners, ward-based senior service network lead agencies, and representatives from the National Caucus and Center on Black Aged and Howard University provided assistance in suggesting churches to be contacted, and reviewed the project's work plan.

The initial plan was to identify African American churches in all eight wards of the city which would develop community coalitions to create programs for African American elders with Alzheimer's disease. However, preliminary outreach work highlighted the need for more basic community education through church outreach, such as explaining the disease as a medical condition, describing the community resources available, discussing the needs of caregivers, and highlighting the role of the faith community in providing support. This conclusion prompted the project to develop a 6-month program plan to educate church members on the basics of Alzheimer's disease.

At the end of the first year, the grant approach was modified to work intensively in four of the eight city wards to provide this education and to work with faith-based organizations to establish the coalitions. Thirty-two churches in those four wards were identified as possible partners. Letters were sent to all 32 churches explaining the project and asking for their commitment. The commitment of several churches is required before coalition meetings can be held and co-chairpersons elected. Although this approach is more time consuming, the project anticipates that it will lead to a broader commitment to the coalition. The Alzheimer's Association made presentations at many churches and community meetings, but recruiting individuals to work on the coalitions has been difficult. Each coalition will have \$8,000 to be spent on programs over the life of the grant. The coalition themselves determined the type of projects and decided on events to increase understanding and awareness, a respite project to enable caregivers to attend Sunday services, and a caregiver respite day care program providing relaxation therapy, counseling and information to caregivers. In addition, a conference is being planned.

Family Care Program—The Family Care Program is an example of “cash and counseling” (Dale et al., 2003). The Family Care Program is modeled on the DC Caregiver's Institute, which was established by the DC Office on Aging with funding from the U.S. Administration on Aging's National Family Caregiver Support Program, but is focused on

African Americans with Alzheimer's disease. In the Family Care Program, which will work with 50 families over 18 months, each family will receive up to \$200 a month in reimbursement for services based on an approved care plan. Caregivers can hire family members or friends to provide services if they choose. While a wide range of services and supplies are covered, the program does have limitations. For example, while funds can be used for personal care services, a trip to the beach is not covered. Although a social worker develops a care plan in consultation with the client and the family, caregivers have a great deal of flexibility in determining what services they receive. It was originally anticipated that many of the referrals would come from the faith-based initiative, but most referrals have come from the DC Caregivers Institute's waiting list and the Alzheimer's Association helpline.

At the time of the site visit, HomeCare Partners had between 25 and 30 clients in the Family Care Program. Clients spend the money on respite care, supplies, medications that insurance does not cover, home modifications, and safety equipment. However, some caregivers did not use all of the funds available because of mental health issues that hinder the caregiver from following through, resistance on the part of the person with Alzheimer's disease to services that the caregiver would like to use, and caregiver misconceptions of the way in which funds can be used. In these cases, the case manager works with the client families to resolve problems.

Montessori-Based Activities Program for Persons with Dementia—The third initiative implements an activity program for persons with dementia based on Montessori principles in four adult day centers. The program is designed to improve engagement with others, reduce agitation or restlessness in social settings, and reduce behavior problems (Camp, 1999). Research conducted by the Myers Research Group suggests that the method developed by Maria Montessori for children can be used to teach cognitive, social, and functional skills to cognitively impaired individuals by breaking down tasks into steps that progress from simple to complex and from concrete to abstract (Bowlby, 1993; Dreher, 1997). Montessori-based activities in the adult day care setting may improve the engagement, social skills, and mood of persons with Alzheimer's disease along with decreasing problem behavior (Judge et al., 2000).

Montessori-based programming was initiated at four adult day care centers. Sessions are scheduled 2 days per week for 1 hour per session. Activities are geared toward African Americans, but literacy is more of an issue than race. Some activities focus on memory stimulation using flash cards, which concentrate on items enjoyed by this population. In addition, the social worker also conducts activities featuring Southeastern states, where many clients have family roots.

3.3 African Americans: Florida

Name of Project

Support Through Alzheimer's Relief Systems (STARS) and Beyond (2004–2007)

Target Minority Population

Low income, rural, and minority seniors, especially African Americans, are the target populations. In 2005, the U.S. Census Bureau estimated that 7 percent of persons age 65 and older in Florida were African American (U.S. Administration on Aging, 2006).

Grant Partners

- Florida Department of Elder Affairs (Grantee)
- Faith-based organizations
- Area Agencies on Aging
- Alzheimer's Association

Project Goals

The project's goal is to increase access to services for individuals with dementia, their caregivers and families residing in traditionally underserved rural, minority, and culturally diverse communities.

Grant Activities

Conducting Outreach Using Faith-based Organizations—The project is using faith-based organizations as sites for educational presentations and as sources of volunteers to conduct Alzheimer's disease outreach. Volunteers are recruited from faith-based organizations and trained by the project conduct outreach in their local communities. Faith-based organizations also provide information about Alzheimer's disease and the grant in their Sunday bulletins. The partnerships with the churches give them the opportunity to learn about the service network and become potential service providers for other state programs (Florida Department of Elder Affairs, 2004). As the time of the site visit for this case study, there were about 80 volunteers, who worked approximately 4 hours on a Saturday.

Volunteers go door to door, providing information from the Florida Department of Elder Affairs. They leave the Florida Department of Elder Affairs' *Consumer Resource Guide* (<http://elderaffairs.state.fl.us/CRG/TC.html>) and a brochure on Alzheimer's disease with the resident. The minority-focused brochures contain information about Alzheimer's disease and how it progresses, Alzheimer's disease service programs, the Department of Elder Affairs mission statement, and the 24/7 Elders Affairs helpline. The volunteers do not know which addresses are the homes of older persons, but information is left even if seniors do not live in the household.

Other Initiatives—Other initiatives of the project include:

- increasing the number of clients with dementia receiving direct services or augmented direct services,
- providing services to cope with wandering associated with dementia,
- providing volunteer access in counties without ADDGS-funded direct services,
- establishing an Alzheimer's disease task force of professionals and community leaders to identify new strategies and resources in the treatment of dementia,

- establishing a priority-setting system for serving clients with dementia and caregivers, and
- expanding the 24/7 crisis intervention information and referral helpline.

3.4 African Americans: Kentucky

Name of Project

African-American Dementia Outreach Partnership (originally Dementia Outreach Lexington) (2003–2007) (name changed at the suggestion of the advisory committee)

Target Minority Population

African Americans are the target population. In 2005, the U.S. Census Bureau estimated that 5 percent of persons age 65 and older in Kentucky were African American (U.S. Administration on Aging, 2006).

Grant Partners

- Kentucky Office of Aging Services (Grantee)
- University of Kentucky Sanders-Brown Center on Aging
- Alzheimer’s Association, Greater Kentucky and Southern Indiana Chapter
- faith-based organizations

Project Goals

The project’s goals are:

- increasing awareness of dementia in the Lexington/Fayette County African American community,
- providing dementia diagnostic services and follow up care for African Americans in their community setting, and
- offering support groups and free memory checkups through faith-based organizations.

Grant Activities

For the first 3 years the project operated in Lexington; the fourth year of the grant extends the project to Louisville, the Kentucky city with the largest population of African Americans. In addition to increasing the reach of the project, the expansion into Louisville also tests the outreach and care model developed in Lexington in another part of the state.

Awareness Outreach—The organizations involved with the grant and representatives from the target community formed an advisory council to guide the project. Relationships were

established with six churches. Project staff arranged with community and church leaders to attend church and cultural center functions, health fairs, and festivals. The outreach campaign includes radio and television public service announcements and brochures developed to educate the community about the disease and where they can go for help. African American graduate students at the University of Kentucky assist in educational outreach, clinical assessment, and family counseling. Pharmacies, groceries, barbers, beauty shops, laundries, and restaurants as well as door-to-door delivery were used to distribute flyers about the clinic and events. The *Branch Out Kentucky Conference*, held in October 2005 at the recommendation of partnering churches, attracted an audience of 350, 95 percent of whom were African American.

Existing educational materials from the University of Kentucky's Alzheimer's Disease Center are modified to accommodate persons reading at the sixth-grade level and focus on personal safety. Past experience at Kentucky Clinic North, the site of the Memory Care Clinic, showed that information concerning dementia is more readily accepted when framed as a safety issue. Clients are referred to the Bluegrass Area Agency on Aging for services that supplement those provided as a part of this grant.

Provide Dementia Diagnosis and Services within the African American Community—The project provides dementia diagnosis and services within the African American community. Free memory checkups are offered by the project, which may reach persons who are not yet willing to see a physician and may identify individuals early in the disease when current medications may be more effective. An African-American nurse conducts initial testing and collects safety and social information in the home. The results for individuals who do not do well on the screening are reviewed by a neurologist, who decides if additional testing is warranted. The goal is to reach 100 patients in the third year of the grant. To evaluate the initiative and to help with recruitment, client satisfaction questionnaires are completed by families attending the clinic.

To encourage use of the clinic, a well-attended open house was held at the dementia clinic, which included free memory testing, an opportunity to meet the staff and physicians, and food and door prizes. Thirteen agencies that work with older people had exhibits at the open house.

Involve Faith-Based Community in Support Groups and a Best Friends Caregiver and Patient Support Program—At the start of the project, the Alzheimer's Association organized support groups run by African Americans. However, after the initial meeting, where only one person attended, the advisory council suggested changing the name to the "Fellowship Group" as a way of reducing the stigma of Alzheimer's disease.

The in-home respite program, based on the Best Friends approach, did not succeed. Although the respite program received excellent support from the partner churches and 18 volunteers were trained, identification of families in need and matching family need with appropriate volunteers was difficult. During the second year of the grant, a decision was made to discontinue plans for the respite program based on feedback suggesting that families were not receptive to having church members come into their homes; families feared that church members would be judgmental. Families felt that they would not be viewed favorably if they were unable to take care of their relatives and they preferred trained professional help rather than friends.

Instead of a respite care program, two educational pieces were developed for the church community—a comprehensive book on Alzheimer’s disease and caregiving and a resource guide listing all dementia-specific services in the Lexington/Bluegrass Area.

SECTION 4

BARRIERS AND STRATEGIES

Alzheimer's Disease Demonstration Grants to States (ADDGS) projects working with minority populations face a number of barriers to the successful implementation of their initiatives. Grantees in the District of Columbia, Florida, Illinois, and Kentucky devised a number of strategies to overcome these barriers. The main issues that had to be addressed include:

- trust from and access to the community,
- cultural beliefs and knowledge about dementia,
- language, and
- the role of the family.

In this section, we outline the hurdles that had to be overcome and the methods that the grantees used to do so in order to serve minority populations.

4.1 Trust from and Access to the Community

Grantees identified gaining the trust of and access to the community and its leadership structure as the most important barrier to successfully reaching and serving minority communities.

These barriers include the following:

- *Minority communities are often wary of people, organizations, and institutions that are not part of the community.* In part, this distrust is the result of perceived or real racial and ethnic discrimination, cultural differences, language barriers, and social class differences.
- *Ethnic and racial minorities may believe that outside organizations “use” the communities for their own benefit and do not contribute to the communities’ long-run well-being.* Referring to perceptions in Florida, one respondent noted that some people in the African American community expected that outside organizations would “come into their communities, get what they need, treat the congregation as lab rats, and then leave, leaving the church in the same condition as it was when they first came.” Academic researchers are sometimes the target of these comments which some observers saw as partly the legacy of the Tuskegee experiment, where some African American patients were not given treatment for syphilis. At the beginning of the project in Kentucky, the ministers on the advisory board asked, “Why should we help the University? What have they done for us?”
- *Minority communities may distrust government agencies, perceiving them as prying into personal finances and other family issues as a condition of providing aid.* Ethnic and racial populations may also be reluctant or find it difficult to complete the

detailed paperwork required for some means-tested government programs. Medicaid, for example, requires that applicants provide extensive information about income and assets and that they provide this information on a regular basis.

Strategies used by grantees to gain trust and access included the following:

- *Projects invested substantial project leadership resources into gaining knowledge about and the trust of the community.* Finding allies in the community was critical to gaining access to groups that could implement the new initiatives. In order to access the community, grantee staff relied on people connected to the community for introductions (e.g., people who go to the community churches and ministers contacting other ministers); respected community cultural traditions (e.g., ate specially prepared food when offered and refrained from taking pictures of women when the culture viewed doing so as inappropriate); and were inclusive in their discussions (e.g., not referring to the community as “those people”). Beyond ministers, many African American churches have a health or social ministry that addresses issues such as Alzheimer’s disease and “first ladies” (i.e., pastors’ wives) are often important entrees to faith-based congregations. According to one respondent in Washington, DC, “A minister in Ward X was the key person to opening the doors which were closed. He arranged for me to make my presentation at a gathering in Ward Y where there were 130 pastors.”
- *All of the grants involved the racial or ethnic community by using strategies such as hiring individuals from the community, working with service organizations with strong ties to the community, locating services within the target community, and establishing advisory committees.* For example, the Kentucky project hired African American staff to work at the memory clinic; and in Washington, DC, the outreach to the faith-based communities was also conducted by an African American. Similarly, community members were recruited as volunteers to provide information and services to the community in Florida. In terms of service organizations, rather than trying to alter the services provided by the Alzheimer’s Association, the Illinois project worked through an association of ethnic organizations that provided services to older people. In Kentucky, the Alzheimer’s Disease Research Center opened a clinic in the Lexington neighborhood with the highest proportion of African Americans. Finally, all of the grants established advisory councils to provide meaningful community input to the projects. Advisory council members give advice to the grant, but they also provide information to the community about the activities of the grant.
- *Three of the grants worked with faith-based organizations whose congregants were African American.* In many minority communities, faith-based organizations provide community leadership and have contact with large numbers of people on a regular basis. Gaining access to these faith-based organizations is often not easy and is best done through people who are familiar with the church and its members. According to one observer, “Be willing to go into the community and sell yourself. The buy-in to the faith-based community is you, not the project or Alzheimer’s disease. It was about me meeting them and them feeling comfortable with me.” As another grantee staff person put it, “The best way [to gain access to the faith-based community] is to ask

someone who is familiar with the faith-based community. What we realized is that the faith-based community may not be in touch with what is going on with Alzheimer's disease, but are in touch with one another. If you get connected with one institution that is connected with another, you tend to gain access to multiple institutions. If you have someone familiar with how faith-based institutions are connected in terms of the number of denominations, organizations, and fellowships, it is a gateway to the community."

In working with African American churches, it is important to emphasize that the grant wants certain things from the faith-based community, but is also giving back to the community. In Florida, the grant emphasized that "our mission is not just to enrich our program, but to enrich the program of the church and to enrich the church's outreach. We are giving churches the resources to help them conduct outreach and expand the church's mission to evangelize....The message is partly that this is a way for the church to meet its mission and that we are trying to help them do what they need to do. Our presentation to the faith-based organizations is about partnerships—how will our church help the community? How will the church help the Stars and Beyond program? How will the Stars and Beyond program help the church? How will the program enrich the lives of the members of the church? It is all about partnering and enriching each other's missions. We will help you reach out into the community and we will provide you the resources."

Another strategy to gain the cooperation of faith-based organizations is to offer them resources over which they have control. For example, in Washington, DC, as an incentive for faith-based organizations to participate, the project provides small amounts of funds that the community coalitions can use for Alzheimer's programs that they devise, such as Sunday respite care, a caregiver day of renewal, and information and awareness events and a conference.

4.2 Cultural Beliefs and Knowledge about Dementia

Ethnic and racial minorities may have different cultural beliefs and understandings about dementia that may impede the use of services.

Barriers related to cultural beliefs and knowledge about dementia include the following:

- *Awareness and understanding of Alzheimer's disease is low in some ethnic and racial communities, especially those facing competing demands such as low income, high levels of unemployment, lack of health insurance, crime, and lack of affordable housing.* Community members may not be aware that Alzheimer's disease is a chronic, degenerative disease with no cure. Knowledge of available services may also be low. As one observer in Washington, DC, put it, "After we started our outreach, we recognized that getting into the community was slower and required more intensive work than we first anticipated. We found that our expectations of people's existing knowledge and awareness of the disease, available services, and conception of the caregiver role was less extensive than imagined."

- *Minority populations may be more likely to identify Alzheimer's disease as "normal aging."* Alzheimer's disease and other dementias are less likely to be considered something out of the ordinary requiring diagnosis and treatment. In addition to not being knowledgeable about the disease, minority populations may be less familiar with what services are available.
- *In some cultures, there may be particular historical reasons that family members have cognitive impairment that are unrelated to Alzheimer's disease.* Some immigrants, such as those from Bosnia, suffer from post-traumatic stress disorder which can produce cognitive impairment and other symptoms similar to Alzheimer's disease, but which is not Alzheimer's disease. In addition, historical experience may cause family members to resist labeling relatives as having mental problems. Some immigrants from former communist or other authoritarian governments may be fearful that a diagnosis of "mental illness" may result in forced institutionalization.

Strategies by the grantees to address these barriers include the following:

- *Grantees were cognizant of cultural differences and modified educational and other materials to better suit the community.* The grants viewed extensive awareness training and basic education on Alzheimer's disease for the community as a necessary prelude to all additional activities. "Memory 101" classes are commonly offered. Grantees produced written and other material that focused on the target population in order for the community to recognize how Alzheimer's disease affected them. The material did not assume a professional level of understanding. Finally, as a way to create messages to which ethnic and racial minorities might be more receptive, some projects focused on the behavioral aspects of Alzheimer's disease and on issues of personal safety.

4.3 Language

Language is a means for people to communicate, but it can also be a barrier to serving minorities and educating them about Alzheimer's disease.

Some of the barriers faced by grantees include the following:

- *In some communities, the ability to speak and read English may be limited.* Immigrants may only understand their native language or may have only limited ability to comprehend written material in English. Even where help is available in an individual's native language, there may be glitches in connecting the individual seeking help with an interpreter. For example, the Alzheimer's Association helpline, the 24/7 Helpline, has extensive translation services available, but accessing the services is dependent on the callers stating their language in English and staying on the line for an additional 30 to 60 seconds for the interpreter to join the call.
- *Commonly used English-language terminology about Alzheimer's disease and cognitive tests may not translate well into other languages.* In some languages, there is not a commonly accepted term referring to the complex of behavioral and

functional problems that English-speaking persons call Alzheimer's disease. For example, the Arabic term commonly used as a translation for Alzheimer's disease has two meanings, one of which is "crazy," which is pejorative. In some other languages, the term sometimes translates as "mentally retarded." Not surprisingly, families are reluctant to categorize their older relatives this way. Similarly, some of the commonly used tests for cognitive impairment, such as the Mini-Mental Status Exam, assume a written language in which there is a forward and a backward, which is not the case in some languages. For example, the Mini-Mental Status Exam asks the respondent to spell "world" backwards, but there is no way to do that in Arabic, Assyrian, Hindi, or Urdu.

To address these barriers, grantees adopted several strategies including the following:

- *Instead of using the difficult-to-translate, emotionally laden term "Alzheimer's disease," grantees used the term "memory loss."* Thus, grantees used a term that focused on the most important manifestation of the disease using an easy-to-use, nonpejorative term.
- *Educational and outreach material was translated from English into other languages set at a modest reading level.* This is not, however, as straightforward as it might seem. Many languages, including Spanish, have different dialects (e.g., Spanish spoken in Puerto Rico is not the same as that spoken in Spain) and levels of formality. The Illinois project, in particular, works closely with its ethnic agency partners to develop translated material and to make sure it is accurate. In addition to being used for the project, these translated resources have been sent abroad and are being used in Pakistan, Syria, and Turkey. In the Illinois example cited above, all brochures for the project that include the helpline telephone number include instructions to say the name of the language in English and to remain on the line to allow the interpreter to join the call. Grantees also made sure that educational materials for families and other nonprofessionals were written at a sixth-grade reading level so that they are understandable to most readers.

4.4 Role of the Family

In virtually all cultures, families play major roles in caring for people with dementia. In minority cultures, families have especially large caregiving responsibilities because of differing cultures and norms, language barriers, reaction to past discrimination, and difficulties accessing services. Some of the barriers that the grantees encountered in providing services to minority populations include the following:

- *Cultural norms establish expectations for families to "take care of their own" without the help of others.* In many cultures, taking care of elderly relatives is a duty and a normal role. As a result, families often do not self-identify as caregivers with a separate or new role; it is just an extension of their ongoing responsibilities. Moreover, in some cultures, to admit to being unable to care for an older family member is simply unacceptable. In this view, seeking outside help or accepting paid or volunteer services is a sign of failure on the part of the family. As a result, referrals

to Alzheimer's disease support groups are often viewed as criticisms of the family. To save face, family members do the best they can without anyone else knowing of their situation. Similarly, many families have difficulty accepting services such as respite care because they do not want others to think they cannot handle the responsibility of caring for their relative with dementia. Where there is not an extended family available to help, caregivers can feel very isolated.

- *Families are often intensely private and see services such as volunteer respite or support groups as "getting into family business."* Many families are uncomfortable with strangers providing care or coming into their homes. Among African Americans, this can apply even to volunteers from the same church. In some cases, they do not trust professionals to keep their family problems private.
- *Respect for elderly relatives may preclude adult children and other relatives telling seniors what to do, even when they are not cognitively intact.* While a sensitive issue in all cultures, adult children in minority cultures may be particularly reluctant to tell relatives with Alzheimer's disease that they should not drive or use the stove because these activities pose a danger to themselves and others or that they should consider moving into some type of supervised living arrangement.

Some of the strategies that the grantees have used to address these barriers include the following:

- *The differences in norms about caregiving are accepted by the grantees and ways are sought to present services in a culturally acceptable fashion.* For example, support groups are recast as educational, social, or spiritual gatherings among people with similar interests rather than as a means to provide emotional or psychological support to burdened family members. As a result of resistance to traditional support groups, the Kentucky grant renamed them "Sharing and Caring Fellowship Hour." Once the groups are together, members naturally begin to talk about the issues of caring for a person with Alzheimer's disease.
- *The family decisionmaking process is acknowledged and services work with rather than against that structure.* The family plays a major role in providing care and in deciding on services for older relatives. For example, the Kentucky Memory Care Clinic found that multiple members of the African American family are involved in health care decisions, and they may not all agree with one another. To help resolve care decisions, a family meeting may be held after the family member has been diagnosed with Alzheimer's disease moderated by the clinic nurse. Observing interactions and facilitating communication during this meeting lays the groundwork for future decisions. In the District of Columbia, the care manager encouraged the involvement of larger family groups rather than just the designated "primary" caregiver. As a result, visits by the care manager often involved three or more family members, with some joining the conversation via phone. This approach provided the extended family with a sense of involvement in the caregiving process. In addition, it often had the unexpected benefit of providing support to the primary caregiver from siblings or others who had previously been only marginally involved. In Illinois, the

grant sought to involve the prestige of respected community physicians to provide legitimacy for their Alzheimer's disease initiatives. Physicians were identified by the participating ethnic providers and then received an informational visit from staff members of the Northwestern University staff person, CLESE, and the ethnic agency.

SECTION 5

SUMMARY AND CONCLUSIONS

One of the main goals of the Alzheimer's Disease Demonstration Grants to States (ADDGS) program is to improve services for underserved populations, including racial and ethnic minorities. Alzheimer's disease among minority populations is of policy concern because of possibly higher risk of Alzheimer's disease (especially among African Americans), the lower level of knowledge about the disease and its progression, and the lower use of services.

The grantees identified four main barriers to serving ethnic and racial minority populations and implemented strategies for overcoming them. The main areas they identified as barriers were (1) trust from and access to the community, (2) cultural beliefs and knowledge about dementia, (3) language, and (4) the role of the family.

5.1 Trust from and Access to the Community

Grantees identify trust and access to the community as the principal barrier to implementing their initiatives. Components of this barrier include:

- Minority communities are often distrustful of people, organizations, and institutions that are not part of the community.
- Ethnic and racial minorities may believe that outside organizations use the communities for their own benefit and do not contribute to the communities' long-run well-being.
- Minority communities may distrust government agencies, perceiving them as prying into personal finances and other family issues as a condition of providing aid.

Strategies used by grantees to overcome these problems include the following:

- Projects invested substantial project leadership resources into gaining knowledge about and the trust of the community.
- Grants involve the racial or ethnic community by hiring individuals from the community, working with service organizations with strong ties to the community, locating services physically within the community, and establishing advisory committees.
- Three of the grants worked with faith-based organizations whose congregants were African Americans.

5.2 Cultural Beliefs and Knowledge about Dementia

Some ethnic and racial minorities have cultural beliefs and understandings about dementia that differ from the mainstream culture that may impede their use of services. Barriers include the following:

- Awareness and understanding of Alzheimer’s disease is low in some ethnic and racial communities, especially those facing competing demands such as low income, high levels of unemployment, and lack of health insurance.
- Minority populations may be more likely to identify Alzheimer’s disease as a part of normal aging.
- In some cultures, there may be particular historical reasons not related to Alzheimer’s disease that family members have cognitive impairment.

The main strategy that grantees use is to be cognizant of cultural differences and to modify educational and other material to better suit the community.

5.3 Language

Language can be a barrier to educating people about Alzheimer’s disease and providing them with services. These barriers include the following:

- In some communities, the ability to speak and read English may be limited.
- Commonly used English-language terminology about Alzheimer’s disease and cognitive tests may not translate well into other languages.

Strategies used to overcome these barriers include the following:

- Instead of using the difficult-to-translate, emotionally laden term “Alzheimer’s disease,” grantees use the term “memory loss.”
- Educational material is translated culturally and linguistically from English into other languages.

5.4 Role of the Family

In virtually all cultures, families play major roles in caring for people with dementia. In minority cultures, families have especially large caregiving roles because of differing cultures and norms, language barriers, reaction to past discrimination, and difficulty accessing services. Some of the barriers that the grantees encountered in providing services to minority populations include the following:

- Cultural norms establish expectations for families to provide care to elders without the help of others.
- Families are often intensely protective of their privacy and see services such as volunteer respite or support groups as intrusive.
- Respect for elderly relatives may preclude other relatives telling seniors what to do.

Some of the strategies that grantees use to address these barriers include the following:

- The differences in norms about caregiving are accepted by the grantees and ways are sought to present services in a culturally acceptable fashion.
- The family decisionmaking process is acknowledged and services work with rather than against that structure.

5.5 Conclusions

Providing culturally appropriate services is essential for people with dementia and their caregivers for three key reasons. First, some minorities are at an increased risk of Alzheimer's disease. Second, minority populations are less likely to be aware of Alzheimer's disease as a disease and are more likely to consider it part of normal aging. Finally, minority populations tend to underutilize services at all stages and are more likely to start using services later in the disease process. Overall, extensive research has shown that health care disparities exist in the United States to the disadvantage of racial and ethnic minorities (U.S. Centers for Disease Control and Prevention, 2007).

The ADDGS program encourages grantees to target services to hard-to-reach and underserved individuals with Alzheimer's disease and their caregivers. As a result, ADDGS grantees are engaged in a range of activities designed to: (1) reduce disparities in service provision to minority populations, and (2) increase access of services by families through innovative service models.

The service models of Illinois, District of Columbia, Florida, and Kentucky are innovative examples that can be replicated in other states and programs. Each of these ADDGS grantee states has demonstrated leadership in developing a range of "promising practices" in serving minority populations.

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